Air Force Exceptional Families – Parent Perspective

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Overview

- Background
- Needs during PCS
- Needs day to day
  - Families
  - Community (feedback and affect change)
- Needs during deployment
- Serving EFM Parents – considerations
- Desired Knowledge, Skills and Abilities
- Summary

Background

- **Exceptional Family Members**
  - **Includes spouses, children, or dependent parents who require special medical or educational services**
  - **Have a diagnosed physical, intellectual or emotional condition**
- **Approximately 15,000 Exceptional Family Member dependent children in AF; numbers suspected to be low**
- **AF currently manages EFM through Special Needs Identification and Assignment Coordination (SNIAC)**
- **AF is only service without Headquarters and/or installation EFM Program Family Support manager**
- **EFM families have needs during PCS, day to day, and during deployment**

Needs during PCS

- **Accurate, up to date information regarding services available at all locations (specific to disability and severity)**
- **Clear, simple, transparent policy on assignment procedures (with compliance)**
- **Effective identification and communication of needs through an objective third party***
- **Objective comparison of needs vs. services and replicable decision making process on assignment***

*** Most effectively accomplished by someone who knows and understands disability, individual child, and family**

Needs Day to Day - Families

- **Assistance with identifying and accessing child care and respite services (remove barriers)**
- **Assistance with enrolling and accessing military (ECHO) and local (Medicaid Waiver) special needs programs**
- **Assistance with identifying and accessing specialty care providers (dental, speech, behavioral, neurology)**
- **Assistance with identifying and accessing appropriate special education programs specific to disability**
- **Crisis support as needed for surgery, major in-patient procedures, emotional breakdowns, severe behavioral episodes**

Needs Day to Day - Families

- **Ongoing assessment of member/family, check of needs and adequacy of services (quarterly, annually?)**
- **Assistance with establishing and maintaining records**
- **Assistance with financial planning and special needs trusts/long term care**
- **Advocacy across all areas**
- **Advice, lessons learned, and strategizing specific to local community and conditions**

Needs Day to Day - Community

- **Establish partnerships with local community providers of child care and respite for special needs children**
- **Ensure current issues regarding accessibility and utility of ECHO and Medicaid programs are communicated on behalf of military members**
- **Ensure issues regarding access to specialty care are communicated back thru chain of command**
- **Ensure issues regarding adequacy of special education services are communicated back to local communities**
- **Facilitate participation in local community support groups, organize/establish military support groups, establish e-mail groups and list serves**

Needs During Deployment

- **Respite care, respite care, respite care**
- **Proactive assistance in evaluating and establishing/ increasing services as needed (counseling, behavioral therapy and supports in the home, see Dr. Cozza, USPHS)**
- **Touch points pre, during, and post deployment to assess needs and access to services**
- **Typical family needs (communication, resiliency training, mission awareness)**
- **Frequent contact and checks on needs and supports in coordination with unit**

Serving Exceptional Families

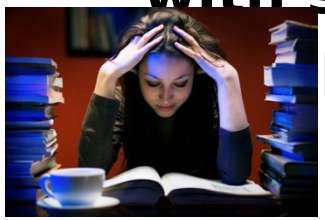
- **Families affected by special needs are unique and different from other customers**
- **Societal norms still tend to indirectly place “blame” on parents for child’s disability, especially behavioral**
- **1 in 6 children in U.S. diagnosed with a behavioral disorder (Centers for Disease Control, 2007)**
- **1 in 91 children diagnosed with autism (CDC, 2009)**
- **Personnel providing Systems Navigation, resource support need to be aware, not perpetuate myths**
- **Cause of disability should not be factor of consideration or influence (recent examples)**

Points to remember…

- **Most parents of special needs children…**
  - **Are sleep deprived**
  - **Don’t have much of a social life**
  - **Don’t have their own hobbies or interests (their child’s disability is their “hobby”)**
  - **Don’t get support from their family, civilian community, or schools**
  - **Place an extraordinary value on time (they don’t have seconds, let alone minutes or hours to waste)**

Points to remember . . .

- **Most parents of special needs children…**
  - **Have difficulty scheduling and completing simple daily living tasks (grocery shopping, doctors appointments, dental appointments, post office)**
  - **Experience financial difficulties (one parent unable to work, costs of care and medical expenses often out of pocket)**
  - **Are constantly worrying about today, tomorrow, and the future for their family and their child**
  - **Are used to and expect adversarial encounters with service profes[illegible]als (doctors, teachers, [illegible]pists)**



Desired Knowledge, Skills, and Abilities

- **Empathy (understanding, being able to walk in parent's shoes, truly understand perspective)**
- **Knowledge of special education and disability law**
- **Knowledge of respective state Medicaid waiver programs, health and human services, and social security administration**
- **Knowledge of TriCare and military benefits, to include active duty, reserve, guard, and retiree (and differences between)**
- **Knowledge of current, research based treatments for a broad range of disabilities and disorders**

Desired Knowledge, Skills, and Abilities

- **Ability to advocate and negotiate**
- **Persistence and patience in dealing with clients and social/medical service systems**
- **Organization and efficiency (every minute is precious)**
- **Proactive, self starting (no current models within AF to follow, Marine Corps and Army are benchmarks)**
- **Thick skinned, ability to not take issues or reactions personally**
- **Combination of Mother Theresa, Sara Connor, Gandhi and Jackie Chan**

Summary

- **Effective systems navigation for special needs families will support and enhance mission readiness**
- **Airmen and families are our greatest resource**
- **Any services provided initially will be greatly appreciated by families**
- **We should fulfill core value of “Excellence in all we do” to make AF program model in DoD**
- **Requires resources (manpower and funding) supported at the highest levels**

The Hilton Family

Year of the Air Force Family

The Vitaliano Family

Year of the Air Force Family

The Tarwater Family

Year of the Air Force Family

The Vance Family

Year of the Air Force Family

The Linn Family

Year of the Air Force Family